

**Written evidence from Baroness Finlay of Llandaff FRCP, FRCGP, FMedSci,  
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**Report to the Select Committee on Public Administration and Constitutional Affairs on  
*Dying without Dignity Report***

This evidence includes my personal perspective on the history that may have contributed to today's fragmentation of services, the postcode lottery and appalling lack of care, particularly in nursing, that are evidenced in Parliamentary and Health Service Ombudsman's (PHSO) report '*Dying without Dignity*'. Despite the enormous advances in palliative care and the strong national support for hospices, the problem remains that, although we know what to do to support people to die well, it is just not happening.

There is a need for a national palliative care strategy to tackle poor symptom control, communication and pain management, and to improve out-of-hours services and the recognition of patients palliative care needs. **My Access to Palliative Care Bill seeks to solve these problems through requiring Clinical Commissioning Groups (CCGs) to commission specific Specialist Palliative Care Services and improve research and education in this field.**

**Background**

Since the 1960's, when the hospice movement started to gather momentum, great investment was made in the dissemination of knowledge and skills to ensure the 'hospice ethos' of care was shared as widely as possible in the voluntary sector and the NHS. However, it was charities rather than the NHS that took up the role of providing better and different end of life care, initially to cancer patients. When the HIV epidemic became evident, the role of hospice service providers widened to non-cancer patients, although some, such as Sue Ryder, had focused on neurological conditions in the early days.

**The NHS did not include palliative care as a 'Core' service and had no strategic plan in place to accommodate hospice services.** As a result, the progress of hospices was often led by individual founders and local organisations, usually with a particular interest in their development. Local fundraising and voluntary contributions usually dictated that services, particularly new hospice builds, **were developed in more affluent areas of the UK.**

Services differed according to their founder and the Board of Trustees, and consequently **became driven by individual interests rather than a comprehensive local needs assessment.** Additionally, a sense of ownership amongst some founders of hospices meant that they fiercely guarded their independence to provide such services.

Meanwhile in the NHS and across medical and nursing education, uptake of formalised education, in basic principles of symptom control and in communication skills to engage in difficult conversations, was initially slow. Significantly, by the 1990's all medical schools had provided education in care of the terminally ill and the majority had links with local providers.

This was facilitated by the recognition of palliative medicine as a specialty in 1989 by the Royal College of Physicians and the establishment, by the Association for Palliative Medicine of Great Britain and Ireland (APM), of a comprehensive medical curriculum in palliative medicine. This consisted of three levels in recommended training: a curriculum for higher specialist training, a curriculum for generalist postgraduate training that focused on all clinicians especially general practitioners, and another shorter compatible curriculum for medical students.

Furthermore, the APM, through its regional network, pushed for palliative medicine to become an examined subject in medical finals. Of the three levels in recommended training, the medical student and the higher specialist curricula have been the most extensively adopted and adapted. However, care of the dying patient features little in higher specialist training for medical and surgical specialties, partly because the training schedule is already too crowded to give adequate exposure to all the core components of each discipline. In palliative medicine education was a major activity from the outset, in large part through an organised national campaign led by the APM to drive up standards of care for dying patients.

However nursing did not have such a nationally cohesive strategy and the roles of specialist nurses were determined in large part by local hospice charities and the national charity Macmillan Cancer Support, who provided pump-priming funding for posts across the UK, usually for three years per post. These post-holders, as Macmillan nurses, were employees of the local NHS and answerable to the NHS employer. Many were working in relative isolation, with large clinical loads and were not always part of a multi-professional team.

This has improved over time, mainly as a result of the requirement of a multi-disciplinary approach recommended in 2004 NICE Guidance on Supportive and Palliative Care for adults with Cancer. Although the focus was again on the palliative care cancer population.

At the same time nursing was undergoing changes due to the elimination of the state enrolled nurse and a new focus on degree qualifications. This appeared to devalue the core human attributes of caring, personal hygiene care and compassionate listening. Even today, care of the dying patient features to varying degrees in the curriculum in schools of nursing and it is certainly not a major component of all undergraduate training for nursing or allied health professionals.

Today's NHS has developed into a heavily managed culture of risk-avoidance, with protocols and guidelines determining much of what should and should not be done. For the majority

of patients, guidelines and protocols have improved safety through applying scientific evidence, and have been essential in eliminating idiosyncratic behaviours by different clinicians. Yet it has had some adverse effects on palliative care. Recording what was or was not done or said as clinical notes has become a major time consuming activity; such recording is important, but particularly in nursing it can be a time consuming distraction from patient care when staffing levels are low. Risk aversion and rigidity in approach can run counter to a service that can provide individualised flexible care to a dying patient.

### **Public Attitudes**

It is often said that in the UK people still don't talk about death and dying. The National Council for Palliative Care, of which I become Chair in September 2015, has undertaken to try to promote a national conversation around death and dying through their Dying Matters initiative. As well their public facing work, they have professionally facing national projects to raise awareness of the needs of patients and are an umbrella organisation and forum for all charitable and NHS palliative and end of life care service providers. They work very closely with the APM, the different specialist palliative care nurses groups and others to disseminate nationally agreed standards, collect data on service provision and foster educational initiatives.

The public conversation about death and dying has developed against a background of some prevailing messages in society. The one that 'over 90% of health care costs occur in the last year of life' is hardly a surprising statistic – given that well people do not access complex health care. Many high cost interventions will improve quality of life and may also prolong life, but relatively few are truly curative.

Messages such as "If you're demented, you're wasting people's lives - your family's lives - and you're wasting the resources of the NHS"<sup>1</sup> may have fuelled a disrespect of the elderly and the frail. It is also worth noting that impaired capacity is estimated to occur in about 40% of patients admitted to hospital, several of whom will have an acute delirium associated with illness.<sup>2</sup> Elder abuse is rife in society at large. The incidence is rising and abuse takes multiple forms including physical, neglectful, psychological, financial and sexual, and is often perpetrated in the persons own home by someone well known to them including paid carers.<sup>3</sup> These attitudinal changes in society have an important bearing on quality of care, given that healthcare workers are drawn from across society and are subject to the same influences on thinking and behaviour as the rest of the population; it is important to recognise that the context of poor care is part of a wider societal problem.

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<sup>1</sup> Baroness Warnock, The Times, October 10th 2008

<sup>2</sup> Raymont V, Bingley W, Buchanan A, et al. Prevalence of mental incapacity in medical inpatients and associated risk factors: cross sectional study. *Lancet* 2004;364:1421-7.

<sup>3</sup> Action on Elder Abuse <http://www.elderabuse.org.uk/Mainpages/Abuse/abuse.html> accessed 24/08/2015

## **Strategies**

At the beginning of this century, the Department of Health in England, led by Prof. Mike Richards, developed a national plan for England and a similar national strategy was produced for Wales under the chairmanship of Viv Sugar. These reports both led to discussions about implementation and funding. Both strategies highlighted evident gaps in provision in some areas and the need for care across the course of a person's final illness, not only in the last days of life, and for care focused on those close to the dying person who are facing bereavement.

The direction taken in England was different to that in devolved health care in Wales. In England work was undertaken, led by Tom Hughes Hallett, then Chief Executive of Marie Curie to create tariffs for end of life work, based on the principle that the money should follow the patient. This depended on commissioners to ensure services adequately met the needs of the population served.

However, there appears to be a postcode lottery in access to hospice inpatient beds for the dying in England. Analysis of death registry data on all hospice deaths in England over the last 20 years has revealed a worrying trend regarding variation of hospice inpatient deaths according to area-based deprivation, reporting: "Inpatient hospice death is more likely among decedents living in less deprived areas than among those living in more deprived areas, and this gap has grown over time".<sup>4</sup>

## **Service development in Wales**

In Wales a different approach was taken. There was a decision that a core level of specialist advice and support should be available wherever a patient is; equity would be impossible to establish due to remote rural areas and urban poverty, but that a principle of fairness should underpin developments. This is because disease and its problems do not respect geography, clock or calendar, or any social groupings; services cannot be rapidly instigated or moved round – they are either there or they are not there.

This approach has resulted in specialist palliative care services being specifically developed in deprived areas, such as around Merthyr Tydfil, and an emphasis on a funding formula that is based on: the population for community services, district general hospital needs for inpatient advice and specialist services such as cancer, end stage assisted ventilation and neurology needed specific expertise input. The formula also specifies the number of hospice beds (or hospice at home notional beds) that should be available for a given population and the minimum number of consultant medical and specialist nursing staff required for each service.

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<sup>4</sup> Sleeman KE, Davies JM, Verne J, et al. The changing demographics of inpatient hospice death: Population-based cross sectional study in England, 1993–2012. *Palliative medicine* 2015; 8: 1-9

Despite every clinical nurse specialist (CNS) in the community being linked to specific care homes, access to nursing homes has proven difficult, with a range of factors at play. Care homes are often privately owned, many staff are hired from agencies on a temporary basis (although about 40 percent move around between homes in an area rather than leave altogether).

Historically, patients in the Nursing Home sector were not included within the CNS's caseload. This is now changing, although it requires time to embed and develop relationships between nursing home staff and the CNS. Formal training is made available to Homes and CNS's linked to nursing homes are able to use every referral as an opportunity to impart necessary end of life care skills and knowledge.

In Wales, provision of services on a 24/7 basis with access to clinical records and a data collection system to evaluate service provision was a priority. Scoping work in 2009 demonstrated that seven-day services would enable the vast majority of out of hours' problems to be dealt with in a timely fashion, with evening/overnight services requiring telephone advice available to all those health care professionals providing direct care. Over the past six years that had proven correct.

This service in Wales now operates with:

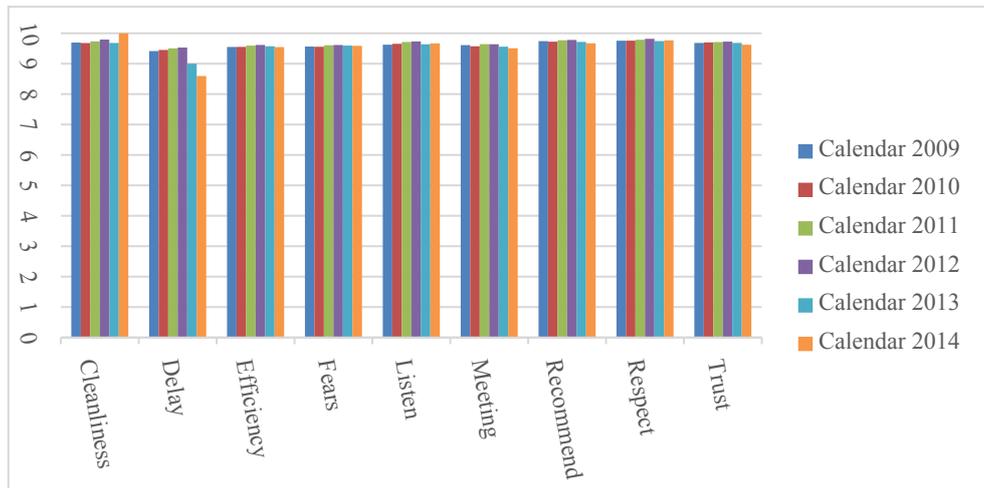
- Seven day CNS services across all sectors
- CNS link for every nursing home
- Medical consultant advice available 24/7
- Access to patient medical records to assist with the assessment of patients
- The availability of direct palliative medicine consultant presence if required.
- A data collection software system that understands at a National and local level how well and how rapidly specialist palliative care teams respond to patient needs.

The only area that is still not fully developed is the Hywel Dda Health Board in West Wales, where medical staff recruitment has proven difficult across all disciplines. However previously vacant posts are in the process of being filled.

Data is routinely collected from all specialist palliative care teams and the report on Wales for 2014-15 is attached as the appendix to this document.

Audit of the palliative care specialist services has been through two national ongoing dynamic audit projects. One is through monitoring the use and effect of the 'Integrated Care Priorities' (ICP) at the end of life; the 'Liverpool Care Pathway' was never implemented in Wales. Instead a simpler guidance and record keeping system was developed which is being further developed to 'Care Directions', taking account of changes such as the All-Wales DNACPR (do not attempt cardio-pulmonary resuscitation) policy and experience of over more than a decade of ICP use.

The other monitoring tool in Wales is the patient voice feedback, though iWantGreatCare, which has shown high levels of patient satisfaction with their encounter with specialist services. 7509 patient returns (some answered by a relative if the person is too ill to respond) over six years show consistently high scores (over 9.5/10) in all domains except for delays in care, which have slightly deteriorated in the past two years (table 1).



**Table 1. Average scores given by patients/proxy on each domain (max=10, min=0) by year (All Wales)**

This drop in scores for delays on receiving care has been attributed to increased service pressures on staff and particular delays in ambulance transport. Of particular importance is the response to ‘were you treated with respect and dignity?’ that has consistently been rated at an average of over 9.7/10 each year.

Other questions explored cleanliness of surroundings for inpatient units or staff in the community, whether services were efficient, addressed patients fears, listened to patients, met their needs and whether they would recommend the service to others and if they trusted the team providing care. The latter two were designed to mirror the ‘family and friends’ test used in England.

The development of palliative care services in Wales has to been largely successful compared to that of England. Wales has successfully worked towards equity of services, providing 24/7 services and clear guidance.

## **Reports into End of Life Care**

### ***Dying without Dignity – Parliamentary Health Ombudsman's Report***

All the cases highlighted were deeply distressing and clearly illustrate a steady stream of complaints that were brought to the PHSO. Sadly, they were not a great surprise. Without adequate education from the outset of healthcare training, professionals in their development get the message that other aspects of healthcare are more important than care of the dying. In some courses, the students are taught by tutors who are not practicing expert clinicians in the field, so the reality and enthusiasm of those doing the job is not brought into the classroom. Students are not routinely required to obtain direct clinical experience with dying patients and therefore are not exposed to potentially inspirational role models in care.

There is a significant failure in most parts of the England to provide access to round-the-clock telephone advice for all those looking after terminally ill and end of life patients, additionally, there is overreliance on web based resources. The complexities of such patients, with their highly individual needs, mean that by the time a nurse or doctor realises they need more information, they need to be able to discuss the case with an expert, to explore these interacting factors and to receive positive support and feedback on having sought advice. Our experience in Wales of trying to set up an email advisory service is that it failed to meet the needs of the patient on whose behalf the advice was being sought. There are extensive guidelines resources that are web based but again there are so many available today that clinicians can only manage those with which they are already familiar.

Drug errors are a major risk when the dose, the route of administration or the type of opioid or analgesic is changed. In Wales, my colleagues Dr Ian Back created a single pan-Wales website for palliative care, accessible to anyone, which complements the telephone advice line. This website includes an opioid dose converter, which has proven invaluable in preventing some prescription errors that would have otherwise resulted in unrelieved pain or in drug toxicity.

Poor care planning is being addressed by a wide range of initiatives. Unfortunately in England there is often failure by one provider to recognise the advance care plans of another, particularly relating to DNACPR decisions. Without common clinical records, whether held by healthcare providers, by the patients themselves or by both, transfer of important information will continue to fail. The ill person will also be repeatedly asked for information which, given the high incidence of impaired mental functioning in the seriously ill, may often be inaccurate or misleading.

The problems of poor out-of-hours provision have already been discussed. As stated earlier, these have been tackled in Wales on a nationwide basis for specialist palliative care services,

with evidence of improved quality of care. There are moves to ensure the clinical palliative care record is available to out-of-hours providers, but this work is not yet completed.

In the PHSO report, perhaps the most shocking of all the chapters was that of a patient on a palliative care ward, where the nursing staff did not recognise and respond to distress, did not use their initiative to obtain a rapid review of the drugs prescribed, and did not feel empowered to contact the consultant on call. One would have hoped that, faced with a distressed patient, an experienced nurse would have taken a telephone order for breakthrough analgesia.

Importantly, the use of telephone orders, which were witnessed by a second nurse over the phone, read back to the prescriber and countersigned as soon as possible by the responsible doctor, have become almost impossible because of risk-averse policies in nursing. There is no strong evidence of patient harm having resulted from the practice, but its cessation has resulted in patients being left waiting in distress. In an ideal world all the possible PRN (if required) drug prescriptions would be written up in advance, but the real world with staff shortages and sudden unpredicted clinical events, is far removed from theoretical ideals.

### **What's important to me – a review of choice in end of life care – National Council for Palliative Care**

This report was produced by the National Council for Palliative Care in February 2015, following a study led by Claire Henry.<sup>5</sup> A number of key themes emerged from wide public engagement. Many people said they wanted choice over their place of care and death; others that they wanted choices over other aspects of their care, such as pain control and involvement of family and those close to them. People also highlighted the need for staff who are well trained and pay attention to all the domains of care (physical, emotional, social and spiritual), which links to the problems of undergraduate and postgraduate training in end of life care previously referred to.

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<sup>5</sup> What's important to me – a review of choice in end of life care. The choice in end of life care programme board. Department of Health. February 2015.

These key themes are illustrated in the report as in the diagram below:



### **Other reports on deficits in care**

There has been a plethora of reports in recent years and sadly, the PHSO's report resonated with many of these that have highlighted inadequate care of dying patients in general care setting, including in their own homes, due to failures in care delivery staff competencies and care systems. The Francis report on Mid Staffordshire NHS Trust was shocking<sup>6</sup>; perhaps the most shocking aspect after the report was a conviction among many in healthcare that this was not isolated. Failures in nursing home care have been investigated both by regulators and by the police at times. Operation Jasmine by the police in Gwent examined care in a series of nursing homes which were glaring examples of criminally negligent care, yet for which attempted prosecution failed.

The Voices report, collating extensive feedback from the bereaved in England, catalogued wide variations in care in different settings. Again hospices fared better than other care settings. Less than half (42 percent) of respondents thought community services were 'definitely' well-co-ordinated and less than a third (31 percent) thought hospital services 'definitely' worked well together with GP and other services outside hospital<sup>7</sup>. Still the hospital is the most common place of death. In 2013, in England, 38% of deaths occurred in NHS hospitals, 21.5% occurred in a care home, 22% at home and 5.5 in a hospice inpatient bed<sup>8</sup>

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<sup>6</sup> Francis R.

<sup>7</sup> Office for National Statistics (2014) *National Survey of Bereaved People (VOICES-SF) 2013*. [online]. London:ONS. Available from: <http://www.ons.gov.uk/ons/rel/subnational-health1/national-survey-of-bereaved-people--voices-/2013/index.html>

<sup>8</sup> Office of National Statistics, (2014). *Mortality Statistics: Deaths Registered in England and Wales (Series DR)*, 2013. [online] Available at: <http://www.ons.gov.uk/ons/publications/re-reference-tables.html?edition=tcm%3A&&-327590>

Other reports that are instructive in revealing failures in access to and provision of end of life care include:

- Demos report 'Dying for Change' 2010 (Leadbeater C, Garber J.);
- More Care Less Pathway 2013 (Neuberger J et. al.);
- Report of the Mid Staffordshire NHS Foundation Trust Public Inquiry 2013 (Francis R);
- Future needs and preferences for hospice care: challenges and opportunities for hospices 2013 (Help the Hospices);
- A Time and a Place 2013 (Sue Ryder);
- Difficult conversations with dying people and their families 2015 (Marie Curie Cancer Care).

### **Contracting for services**

Delays in accessing specialist palliative care for diagnosis and management of distress are in part exacerbated by the variable nature of service provision. If no service is contracted for, it cannot be accessed when needed.

As background to my Access to Palliative Care Bill, a freedom of information request was sent to all Clinical Commissioning Groups (CCGs). Although analysis of all the data is not yet completed, it is evident from the responses that there is wide variation in the numbers of hospice beds per 100,000 population, in levels of other services and in whether there is any availability at nights and weekends of specialist palliative care services or even telephone advice. Early analysis appears to suggest that at least 10% of CCGs fail to commission any weekend services, 14% are without 24/7 telephone advice and 21% do not provide support for routine education in palliative care.

Sue Ryder recently conducted a similar study and the findings revealed a lack of all-hours palliative care support. Only 44% of areas offered a dedicated 24/7 palliative helpline or coordination centre, only 34% of areas had out-of-hours palliative advice, support and coordination and only 8% of areas had a dedicated 24/7 palliative helpline for patients and carers as well as a 24/7 coordination centre. Sue Ryder found that 82% of the public expect that support and advice should be available 24 hours a day for those who are dying, and 84% felt it was important for politicians to prioritise the issue of 24/7 support for people who are dying<sup>9</sup>.

Looking at all the evidence and initiatives that have been undertaken over the past quarter of a century, it seems that more of the same will not bring about the sea-change that needs to occur in care of the vulnerable and dying.

<sup>9</sup> Sue Ryder (2015) *Dying Doesn't Work 9 to 5*. [online] <http://www.sueryder.org/how-we-help/Policy-and-campaigns/Our-campaigns/not-9-to-5/facts>

## **The Access to Palliative Care Bill**

My private member's Bill has been written to specifically try to find a solution to the problems in the PHSO's report and to meet the requests from patients in the Choices Review. It builds on the experience from Wales where measures have been put in place to try to meet need and would require CCGs to commission services, core education in care of the terminally ill across all disciplines and promote research to move forward the frontiers in the field.

The Bill had its first reading in the House of Lords on 1st June 2015 and is due for its second reading on Friday 23rd October 2015. A wide range of Hospices, charities, and medical organisations have indicated their support for the bill, recognising it as a fundamental step towards improving end of life care across England.

Clause 1 creates a duty on all CCGs to provide support to those with palliative care needs, especially access to pain and symptom control, support to meet their preferences in care, such as the provision of special communication and physical aids or psychological, social or spiritual support. As such clause 1 covers the right of everyone to receive care at the end of life.

Clause 2 requires CCGs to commission specialist palliative care services and specifies the minimum of such a stipulation, including seven day services, advice to other clinicians, adequate specialist staff in place, a single point of contact for patients and their families, and appropriate systems to ensure information transfer. It also stresses the need for services to be integrated.

Clause 3 focuses on education and training by requiring all employers to verify training has occurred, particularly in pain control and that neglect of a person's analgesic requirements can be a failure of a duty of care. Other core topics are communication skills, the importance of the Mental Capacity Act for palliative care patients and that the needs of the bereaved must be met. It also requires a specific focus of attention is on children and young persons who are being bereaved. This clause requires providers of education and training to teach these core areas, with a particular focus on undergraduate education and generalist postgraduate training. It also requires that these competencies are assessed.

Clause 4 requires that specialist palliative care teams are able to be involved in research and in the dissemination of research findings, to enhance their role as a local resource to others.

Clause 5 requires the Care Quality Commission to look at end of life care as part of its inspection processes

Clauses 6-8 provide definition of its scope, definitions of specialist palliative care professionals and clarifies that the Bill applies to England only.

The bill would help to solve the failures in care highlighted in *Dying without Dignity* as follows:

<b>PHSO topic area</b>	<b>Access to Palliative Care Bill</b>
Not recognising that people are dying, and not responding to their needs:	Clause 1 Clause 3.1.a
Poor symptom control	Clause 2 Clause 3.2 and 3.3
Poor communication	Clause 1.d Clause 3.1.b
Inadequate out-of-hours service	Clause 2.2.d and 2.2.g
Poor care planning	Clause 1.b and 1.c
Delays in diagnosis and referrals for treatment	Clause 2.2.e and 2.2.i

## **Conclusion**

Palliative Care has taken great strides since its inception. The UK is the world leader in end of life care and its Hospice Care is admired from abroad. However, reports have repeatedly shown deficits in care and room for improvement. My Access to Palliative Care Bill seeks to build upon the experience of good care in Wales to provide equitable access to the support and care needed by patients approaching the end of life.

*September 2015*

## Appendix

### **End of Life Care Profile - Wales: April 2014-2015**